

# Policy & Systems Change

**A practical framework for analyzing how rules, funding, accountability, access, and institutional design shape disability safety and autonomy**

*Evidence-informed • person-centered • rights-respecting • implementation-focused*

## SYSTEMS PRINCIPLE

Individual good intentions cannot compensate for a system whose rules, incentives, information flows, or accountability structures repeatedly produce the wrong outcome. Systems change asks what must be redesigned so the safer, more autonomous outcome becomes easier to achieve and sustain.

## 1. The six levers of systems change

### Law & rights

Statutes, regulations, due-process protections, nondiscrimination duties, consent and decision-making law, reporting requirements, and enforceable rights.

### Funding & eligibility

What services are paid for, who qualifies, what settings are reimbursed, rate structures, workforce incentives, and whether funding follows the person's goals.

### Organizational policy

Internal rules governing access, privacy, restrictions, incident response, complaints, supervision, accommodations, and person-centered planning.

### Practice & workforce

Training, staffing, role clarity, professional competence, turnover, supervision, communication access, and implementation fidelity.

### Data & accountability

What is measured, who reviews it, whether patterns are visible, whether complaints are protected from retaliation, and whether corrective action is verified.

### Cross-system coordination

How health, education, disability, child/adult protection, justice, housing, transportation, employment, and community systems exchange information and assign responsibility.

## 2. Policy analysis: ask these questions before proposing a solution

- ☐ What problem is being solved, and how is it measured?
- ☐ Who experiences the problem most directly?
- ☐ Whose voice is missing from the policy design?
- ☐ What current rule, incentive, funding stream, workflow, or power structure helps produce the problem?
- ☐ What rights or legal duties apply?
- ☐ Does the proposal increase or reduce autonomy?
- ☐ Could the same safety objective be achieved less restrictively?
- ☐ Who pays, who implements, and who benefits?
- ☐ What workforce or accessibility capacity is required?
- ☐ What unintended harms are plausible?
- ☐ How will disparities be monitored?
- ☐ What outcome would show the policy actually worked?
- ☐ Who owns corrective action if it does not work?

## 3. Funding and eligibility shape real choices

Policy can promise choice while funding only a narrow set of services or settings. Analyze not just formal eligibility but practical availability: provider capacity, rates, transportation, waitlists, workforce, geography, language, communication access, and whether services can be individualized.

- Map the funding source and allowable uses.
- Identify incentives that reward institutional convenience over individualized outcomes.
- Check whether the person can change providers without losing essential support.
- Examine whether reimbursement supports prevention and coordination, not only crisis response.
- Measure service availability, not merely program authorization.

## 4. Guardianship, decision-making authority, and less restrictive alternatives

Guardianship law is state-specific. National disability policy has increasingly examined alternatives such as supported decision-making. ACL describes SDM as one alternative in which the individual retains decision-making rights with chosen support. Evidence on implementation is growing but remains incomplete, so policy should include safeguards against undue influence and mechanisms for review.

- Require individualized consideration rather than diagnosis-based assumptions.
- Make less restrictive alternatives visible and usable before broad rights are removed where law permits.
- Specify the scope of any substituted authority.
- Create review and restoration pathways.
- Protect access to independent information and advocacy.

## 5. Accessibility is infrastructure, not an accommodation afterthought

For covered state and local government entities, DOJ's Title II web/mobile rule sets WCAG 2.1 Level AA as the technical standard, with 2026 interim-rule compliance dates of April 26, 2027 for entities serving 50,000 or more people and April 26, 2028 for smaller entities and special district governments. Legal applicability and exceptions should be checked against the actual entity and content.

- Budget accessibility into procurement and design.
- Require accessible documents, forms, portals, meetings, and complaint systems.
- Test with disabled users, not only automated tools.
- Track accommodation requests and recurring barriers as system data.
- Do not make the person repeatedly prove the same access need across departments.

## 6. Accountability architecture

A policy without ownership, monitoring, escalation, and correction is largely aspirational.

| Accountability element | Minimum question                                                              |
|------------------------|-------------------------------------------------------------------------------|
| Standard               | What exactly is expected?                                                     |
| Owner                  | Who is responsible?                                                           |
| Measure                | How will performance be observed?                                             |
| Access                 | Can affected people report concerns accessibly and privately?                 |
| Protection             | How is retaliation prevented and addressed?                                   |
| Escalation             | What happens when the first response fails?                                   |
| Pattern review         | Who looks across incidents, programs, locations, and time?                    |
| Corrective action      | What must change, by when, and who verifies completion?                       |
| Transparency           | What can be reported publicly without violating privacy?                      |
| Learning               | How are findings converted into training, policy, funding, or design changes? |

## 7. Cross-system failure analysis

When harm occurs, avoid stopping at 'who made the mistake?' Ask why the system allowed the failure to persist.

☐ What warning signals existed?

- ☐ Which systems held separate pieces of information?
- ☐ Where did communication stop?
- ☐ Was responsibility ambiguous?
- ☐ Did policy discourage action or reward delay?
- ☐ Was the person able to communicate and participate?
- ☐ Were accessibility barriers mistaken for noncompliance?
- ☐ Did anyone verify that the referral or corrective action was completed?
- ☐ Had similar events occurred before?
- ☐ What system change would make recurrence less likely?

## 8. Outcome dashboard: measure what matters

- Safety: preventable harm, abuse/exploitation reports, repeat incidents, retaliation, emergency use.
- Autonomy: meaningful choice, decision participation, restrictions, supported decision-making access.
- Access: communication accommodations, digital/physical accessibility, transportation, wait times.
- Participation: education, employment, community activities, relationships, civic participation.
- Continuity: successful referrals, closed-loop follow-up, transitions, provider turnover.
- Equity: outcomes stratified appropriately to identify disparities without stigmatizing groups.
- Experience: person-reported respect, control, understanding, trust, and ability to seek help.

## 9. Policy brief template

### Problem

Define the problem with population, geography, timeframe, and verified evidence.

### Current system

Describe the law, policy, funding, workflow, and accountability structure now.

### Affected voices

Document lived-experience and stakeholder input, including disagreement.

### Options

Present more than one feasible policy option when appropriate.

### Impact analysis

Safety, autonomy, access, equity, workforce, fiscal, implementation, and unintended effects.

### Recommendation criteria

State the criteria used; separate evidence from value judgments.

## Implementation

Owner, authority, funding, timeline, training, accessibility, data systems.

## Evaluation

Baseline, measures, reporting frequency, review point, corrective-action trigger.

## 10. Systems-change test

### BEFORE CALLING IT REFORM

Ask: Did the change alter the rule, incentive, resource flow, accountability structure, access pathway, or cross-system workflow that produced the problem - and are outcomes being measured? If not, it may be an activity, training, or awareness effort rather than systems change.

### IMPORTANT

Educational resource only. It is not individualized legal, medical, mental-health, emergency, or case-specific advice. Guardianship, mandatory reporting, consent, education, Medicaid, employment, and disability-rights requirements vary by jurisdiction and setting.

## References & trusted sources

Source hierarchy: current federal/public-health guidance and rights standards; systematic reviews and evidence syntheses; then supporting peer-reviewed studies. Legal requirements vary by setting and jurisdiction.

1. Administration for Community Living. Person-Centered Planning. [Source](#)
2. Administration for Community Living. Supported Decision Making Program. [Source](#)
3. National Council on Disability. Beyond Guardianship (2018). [Source](#)
4. U.S. Department of Justice. Title II Web and Mobile Accessibility Rule fact sheet, updated for 2026 IFR. [Source](#)
5. U.S. Department of Justice. ADA Effective Communication. [Source](#)
6. WHO. Global report on health equity for persons with disabilities (2022). [Source](#)
7. Kersten MCO, et al. Knowledge sharing and application in intellectual disability care: systematic review (2018). [Source](#)

### EVIDENCE INTEGRITY

Where evidence is mixed, emerging, or primarily qualitative, this resource says so. Rights-based standards and legal requirements are not presented as randomized-trial findings, and associations are not presented as causation.

